

Get to Know The Arc

Mission Statement

The Arc Montana promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. The Arc Montana is an affiliate chapter under AWARE Inc.

Who Is The Arc?

If you ever have a child, family member or other loved one diagnosed with any type of I/DD, you will quickly come to realize just how invaluable The Arc is, and come to appreciate in a new way all that The Arc does.

The Arc is the largest national organization of and for people with intellectual and related developmental disabilities and their families, promoting and protecting their human rights and actively supporting their full inclusion and participation in the community throughout their lifetimes. We foster respect and access, giving people with I/DD the power to achieve a full and satisfying life through a strong grassroots network of 140,000 members affiliated through more than 700 state and local chapters across the nation. At the national level, a 22 member national board of directors and a delegate body of representatives from each chapter guide The Arc's work. National headquarters staff located in Washington, D.C. carry out their decisions and directives.

When Was The Arc Founded?

The Arc was founded in 1950 by a small group of parents and other concerned individuals. At that time, little was known about the condition of intellectual disabilities (then referred to as mental retardation) or its causes; there were virtually no programs and activities in communities to assist in the development and care of children and adults with intellectual disabilities and or to help support families. In the early days the organization worked to change the public's perception of children with intellectual disabilities and to educate parents and others regarding the potential of people with intellectual disabilities. The Arc also worked to obtain services for children and adults who were denied day care, preschool, education and work programs. In 2010, The Arc celebrated its 60th anniversary.

Why Is The Arc Needed?

The Arc works to ensure that the estimated 4.6 million Americans with intellectual and related developmental disabilities have the services and supports they need to grow, develop and live in communities across the nation. These services include, but are not necessarily limited to, early intervention, health care, a free and appropriate public education, and supports for their families. For adults, services and supports may include preparation for employment, help in finding a job, independent living skill training, leisure and recreation activities and any other supports needed across the lifespan.

How Does The Arc Carry Out Its Vision?

The Arc is recognized as the foremost partner for families and people with intellectual disabilities to support and enhance the quality of their lives. The Arc does this through advocacy on behalf of individuals and families at all levels of The Arc and in the legislative, systems and individual advocacy arsenals. Providing information and technical support to individuals, families and organizations assists them in fulfilling their dreams. Advocacy takes place at the personal, local, state and national levels. Locally, individual advocacy is available through every local chapter of The Arc. At the state level, advocacy occurs with the executive and legislative branches of government, administrative agencies, school districts and other providers. At the national level, advocacy opportunities exist with regard to influencing federal agencies, policies and funding for disability programs and services.

The Arc also educates policymakers, people with intellectual disabilities, service providers, families and the greater community on best practices and issues that impact people with intellectual disabilities and their families. The Arc's is a national force that creates the environment and the opportunities for people with intellectual disabilities and their families to have choices as they live their lives in the community.

How Can I Get More Information?

Please contact Mary Caferro at mcaferro@aware-inc.org or 406.461-2384.
For more information about The Arc and its activities, visit www.thearc.org.



 Twitter: [@TheArcMontana](https://twitter.com/TheArcMontana)

 Facebook: [The Arc Montana](https://www.facebook.com/TheArcMontana)

My name is Joyce Moore. I am looking for a hero, someone who can help me care for the needs of my son, 17 years old, who has Autism Spectrum Disorder.

My family has faced the challenges of his neurological differences all his life, but the past 5 years have presented enormous difficulties. I have heard it said that Autism combined with adolescence is from the pit of hell. I agree. We were able to handle Nicky's behaviors and thinking differences as a family, even to the extreme of home-schooling, until Nick was 14. Then we reached out for help from public school. That system failed us miserably, resulting in even worse behaviors and PTSD symptoms. The problems were eventually worked out, but the damage was done. During that time, we hit our first crisis that sent him to Shodair Children's Hospital. This seemed like the end of the world for us, but it ended up opening doors for us to get services from Aware Inc and their psychiatrist.

For a while, we made progress with the help of Aware Family support specialists and therapy aides, family friends who helped with respite, his therapist/counselor, and us, his devoted family. However, with raging hormones and the harm he suffered from the former school situation, Nicky's behaviors became more and more aggressive and frightening. We faced the "end of the world" again when we just couldn't go on without more intense help. We were advised to send him to Acadia Healthcare in Butte.

The Acadia experience was a nightmare. From the beginning, we were able to see that their techniques were not designed for youth on the Autism Spectrum. They removed supports we had all been using to teach and calm him. Their level system was a constant frustration because it set him up for failure. He was physically assaulted, resulting in a black eye and chipped tooth, so he learned to fight and discovered he enjoyed the sensation. Our family involvement was viewed as interference by Acadia staff. They admitted they didn't really know how to work with parents who stayed involved with their child. After 4 months, we were thrilled to be able to move Nicky to a local Aware therapeutic group home.

The group home experience lasted 6 months. In ways, Nicky seemed to be improving, then he began to regress. We don't know exactly why this happened, but we all understood that this group home was not designed specifically for his Autism needs. The staff worked very hard to learn about Autism and we are so grateful for their efforts, but after one of his "explosions", he had to be sent to Shodair again and was not invited back to the group home. He was deemed "in need of a higher level of treatment".

My husband and I refused to accept any "higher level of treatment" that wasn't designed for Autism. The needs of this disorder are so complex, and it was obvious he needed trained experts to really help him. Shodair searched for placement and found Yellowstone Boys and Girl's Ranch in Billings. When contacted, YGBR declined the request for Nicky to go there because they require residents to have an IQ of 80 or above. This denial meant Montana has no placement for our son. Shodair staff recommended we send him to Utah. The thought of sending our precious child so far from us that we couldn't even visit him, was devastating to us. After seeking advice from trusted professionals, we decided this was not the way we wanted to go. We opted to bring him home.

Having Nicky at home is a huge challenge and we are fully aware that we are facing a tough road ahead. Nicky is high-energy, high-intensity, and sensory-seeking. He is smart in unusual ways, like being able to quote lines from all his favorite movies or tell you the actors' names and all their previous movie rolls. He can sing all the songs from our church's Vacation Bible School from the past 10 years. However, his IQ scores show 64 and he thinks much like a 6-year-old. He asks hundreds of questions every day. My grown daughter has expressed our home life like this: "Mom, being in your home exhausts me! I feel worn out after being with him." He is definitely a challenge, but we are devoted to the task. We are enrolled in an online ABA course to help us study, train and practice the techniques proven to help kids like our son.

This is a small piece of our story. I seek your help because we desperately need help for our son and help costs money. I have studied Autism with intensity since Nick got the Autism diagnosis and have sought out help for him so many times over the past 10 years. Over and over we have been denied. We feel cheated. We feel robbed. Montana has failed us; let me count the ways.

1) The state of Montana has failed us by not requiring school teachers to be trained to work with children on the Autism Spectrum. Montana teachers with a special education endorsement may actually enter the classroom with little or no training about ASD. Our school district set us up for disaster by allowing our special needs son to be taught by someone who had no training or experience and demonstrated a resistance to being taught. Because of her lack of experience and training, she dealt with Nick's behaviors by calling in the school resource police officer, who was also untrained in matters of mental health. His methods were to parade Nick through the school in handcuffs and write citations that involved us in the criminal justice system. As a result of this maltreatment, we had a series of 12 meetings with school staff that were unsuccessful in bringing change. The environment at that school became so hostile, we demanded a permissive transfer to another school. It has been suggested to me, recently, that Nicky probably is now suffering from Post Traumatic Stress from that abuse. Several professionals have told us we should have sued the school district. It has become apparent that they were afraid we would. The damage done at Great Falls High School created behaviors and problems in Nicky we still deal with today.

2) The state of Montana has failed us by making the mental health system dependent on Medicaid, then making it impossible for many families to qualify for it. Working people, like us, cannot afford good health insurance, but still can't get Medicaid help for our son because of our salaries. For several years, Nicky was covered by Healthy Montana Kids. For this, we are eternally grateful. We received medical help from HMK that we could not get before, and it proved to be a wonderful program. However, we continued to hear "You aren't eligible for this program because you don't have Medicaid" or "If only you had Medicaid, we could help you".

3) The state of Montana has failed us by having inadequate residential placement for adolescents and young adults with Autism. You can see, from my story, the frustration and heart break we have experienced from seeking proper placement for Nicky and either having him placed in facilities not equipped for him, or being denied help because none was available in the state. This is a situation that is going to be overwhelming for this state in the near future. We are only the first of a possible landslide of families who will be needing this kind of help very soon. If families can't get proper help for their loved-ones, the money not spent to help them will end up being spent to house them in prisons. I recently attended a conference with Dr Peter Gerhardt who works with adults with Autism Spectrum Disorder in New York. Most of the people he works with are incarcerated or addicted to drugs. Is this really the way we want to deal with people like my son?

4) The state of Montana has failed us by not providing the funds needed to pay higher salaries to Child and Family Support Specialists and Behavior Support Coordinators. These are the people who do the "dirty" work with kids like my son. They are the ones who need to put in the hours of work to teach and re-teach skills these kids need to function in life. Their profession has a terrible rate of turn-over because they are underpaid and under-trained. Since January of 2011, my son has had to get to know, then lose 8 different individuals employed by Aware in these positions. (Change is very traumatic for people on the Spectrum!) The recent Children's Autism Waiver has served to give us data proving the best practices and techniques really do improve success for ASD children. Kids like Nicky learn when lessons are repeated and practiced until the concepts are imprinted as pathways in their brains. When the state applies its resources to the right kind of therapies and treatments, people like my son WILL SUCCEED! Wouldn't it make sense for the state to put its funds into paying better salaries to the CFS's, BSC's, or in-home aides so these kiddos wouldn't have to eat up state money by needing room and board at a therapeutic group home or institution?

Montana is a state that needs to make radical changes to its system in providing for those with developmental and mental health issues. Montana is my family's home. We have loved this state for over 30 years. Our precious son was born here. His friends are here. His home is here. People like Nicky CAN be taught and helped. He doesn't have to end up as a prison inmate or a drug addict. He CAN be helped. We, his family, are committed to seeing him get the help he needs. Please, please hear my story and do your part to make a difference for families like us.

My name is Carolyn Love and I have a 21 year old daughter with multiple disabilities. She has been diagnosed with ADHD, Expressive Language Disorder, Developmental Dyspraxia and a Cognitive Disorder with Amnesia Type Findings from Viral Encephalitis.

She has been on the Developmental Disability waitlist for 3 ½ years thus far. Due to changes in state policy approximately 2 years ago, now she is not expected to receive services for 10 to 20 years. Before the policy changes, the state was divided up into regions. Each region handled their own waitlist and the wait to receive services moved much faster. If chosen for a slot, the person was able to stay in that region if he/she chose to do so. Now everyone is on one big statewide waitlist.

The only way to receive services faster is for her to be in an emergency situation such as both parents passing away or becoming homeless. She would then be thrust into yet another emergency having to deal with very unfamiliar surroundings and people. This would be a very difficult situation even for a person without a developmental disability.

However, let's say she is picked to receive services. Due to policy changes she may not be able to stay in the surrounding area where she is familiar. She would have to go wherever there would be an opening that matched her needs and the money attached to her plan. This is very concerning to us as parents as we are very involved in her life and want her nearby. And I believe we deserve to have it that way.

Also, we are ranchers and live in a rural area which presents a whole other set of challenges. We do not live near other families with similar situations and are unable to carpool, network, socialize, etc. I do not work outside the home so that I can care for her. Her dad and I do not feel she can be left alone in the house for very long for safety reasons. For example, during the summer months we have a much greater chance of fire in the nearby fields and trees. However, there are times when I do need to leave and help with the ranch. She is then left in a potentially unsafe environment. She would not know what to do if we were in some kind of accident and did not come back home. My husband also works out-of-state and must travel several times during the year. When he is away I have added responsibilities, as you can imagine.

Another concern is the fact that when a child turns 21, he/she no longer receives any services until he/she is called to receive Developmental Disability services. That is potentially a lot of time that could be used to build skills such as self help, social, job skills, safety, etc. At this point without constant help the adult may regress and not become a productive member of society.

Doing some research I have found at least 4 states that do not have any waitlist for Developmental Disability services. Would it not be beneficial to at least look at their

state models and see if Montana could use any part to better serve the people on our waitlist?

Also, it is my understanding that the current governor wants a 300 million dollar budget surplus. While I am all for being fiscally responsible, this seems a little over the top when this is actually the people's money and could be used to serve the people of Montana.

My 13 year old daughter, Taylor, has Down syndrome and is a bright and lively person. She is an active participant in so many events which show in her recently being placed on the cover of the local high school newspaper for her skills in Special Olympics while also strutting her stuff down Sear's fashion runway as a top model. She is happy, kind, considerate, passionate, and above all else honest. This is everything you want for your child isn't it? Well my husband and I, like so many other parents out there, want one more important piece of the puzzle for her.....an EDUCATION.

The last 10 months of our lives we have found out that giving Taylor an education does NOT have to be a fight. It does NOT have to mean being an aggressive and downright angry parent towards others. It also does NOT have to be meaningless and nonexistent. The catch you ask? We Can NOT live in the state of Montana to get that for her. My husband, Jason, has been working in the oil fields of North Dakota for a little over two years now and after a year and a half of being away from all of us, we made the decision to go to him. There are no homes available for sale in most of Bakken country so we did what most families are doing to stay together. We bought a 5th wheel and lived in a man camp. About three months ago, after one of the harshest winters on record, we unfroze ourselves and headed back to our empty home in Great Falls. Coming back home had some wonderful merits to it. Taylor was able to start Special Olympics with her old friends, we were around our other family, and we were comfortable in a home with a solid foundation again. We also found ourselves landing face to face with an incredibly difficult decision in our lives. Because of the lack of education Taylor was receiving here.....again.....do we stay and give up her rights to a decent education or move back to North Dakota permanently and away from all our friends and family so that she has a chance to become a strong and independent young woman which is HER RIGHT.

This school year, Taylor started the 6th grade. She was supposed to be in 7th grade, however, we held her back in order to help give her that extra push she needed in her reading, writing, and math curriculum. She was beginning this new year at about a 1st grade level in all three areas. Her IEP was NOT where we wanted it, but teachers here in Great Falls, Montana would not change it. She lost her occupational therapy because she was not disabled enough for it. Again, she has Down syndrome (a form of mental retardation) so how disabled does she have to be? She was only getting 16 minutes a week (not a typo) for speech therapy. And she no longer qualifies for summer school either. Where does that leave us.....and her? Not in very good shape to get ahead of the game that is for sure. Once again the education system in the state of Montana was telling us to quit working with our daughter and keep her dumb in order for her to qualify to get ANY type of help with programs and funding. If we chose to work hard with her so she is successful she would have all of the programs and funding taken away.

Taylor did start her 6th grade year in Stanley, ND. I found that this town of just over 2,000 people had a school with a heck of a special resource program in it as well as exceptionally well trained teachers and paraprofessionals. At first, I thought it might just be that town, however, after making many new friends in the Minot, ND area, I found that almost every school district out there was on even playing fields. Every child with a disability was given so many hours of Speech, Occupational, and Physical Therapy based on their needs. They were also given respite care, Medicaid to cover huge medical costs (not based on income but disability alone), and many other needed services that you CANNOT find here

in Montana. There in North Dakota, you will find no waiting list for group homes or medical care because they fund these programs to help parents have options and to be able to make choices for their kids. With that being said, Taylor left North Dakota reading and writing at a 4th grade level (she accomplished this in 6 months) and math at almost a 5th grade level. She was receiving all the Speech and Occupational therapy that she needed. She also had her own paraprofessional at the school to help give her the extra one on one attention to get her there. She was being set up to succeed.

Since being back in Montana, Taylor has regressed back to a second grade level in all three above curriculum because the teachers here won't work with her or give her the material she was doing in North Dakota. She has lost all occupational and we get that whole 16 minutes a week in speech again. She is on a year to two year waiting list for outside speech and occupational therapy. She is bored in school and does not like going anymore. And our tour through East Middle School gave us absolutely no peace of mind. They stated that we need to stop Taylor's educational program and start focusing more on life skills. SAYS WHO????? Not us. Not ever. She deserves both an education and to learn life skills. She is only going to be in 7th grade. Our state doesn't quit educating our regular ed peers at 7th grade do they? So what is the true difference?

Like many other states, North Dakota has invented programs and funding for people with developmental disabilities. They make sure that all of their residents are taken care of and receive their rights as American citizens. Why can't Montana do the same for all of their residents? This is not about reinventing the wheel folks. It's about taking something that works from another state implementing these plans and placing it into our own system here in Montana.

Right now, our family has to make the decision to stay HOME (here in Montana) and continue struggling and fighting with Taylor's education, medical, and life choices or to sell our house and leave the state we love to allow our daughter to receive the education she and every kid in the United States of America have the right to get. With this being stated I am asking the people who write our laws to help not only my family but every family in the great state of Montana who have children with developmental disabilities to get the funding, programs, training to teachers and other educators, and medical care to help make each and every one of our children successful and happy in their lives and in our communities! These children and young adults are just as much a productive part of our society as you and me. We all need to work together to make one another stronger and better.

Thank you kindly for your time,

Robyn Schwecke
Daughter: Taylor Bailey
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Great Falls, MT 59405
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April 28, 2014

To Whom it May Concern,

I am a grandparent raising 2 grandchildren, ages 11 and 13 year.

The 13 year old is diagnosed with aspergers syndrome . A bright boy with brain connections very different from the average teenager. Immaturity is a primary issue and coping in regular large classroom of peers is very difficult. He becomes disruptive loud and unable to do as teacher asks of him in these situations. He usually becomes remorseful and sorry about acting out afterwards but unable to help self at the time.

He is unable to participate in science and social studies, this year, because of this. Science is one of his favorite subjects and likes it so, I believe it is imperative to provide resource rooms with fewer pupils so they can have a chance to learn and take part in subjects ,that they are not coping well in, in the larger classroom setting.

My other issue is not having a childcare that takes older children like our grandson. He is not able to be left by himself for any length of time or will be taking something apart , or into things he is not supposed to be in, as seems unable to control impulses .

I would like to see some type of care offered for these children that are not prohibitive because of the cost.

YDI does an excellent job of providing classroom help to keep him focused and handling stresses of classroom. We are pleased to have this help and would like to see it extended into summer months.

Aware does a good job of keeping appointments with Psyc hiatrist for evaluation and medication refills. They also refer us to programs useful to us in raising boys.

We sincerely hope the schools can provide the resource rooms needed for children like our grandson so they can reach their full potential.

Sincerely

Sheila Yuhos
3242 4th Ave So
Great Falls MT 59401
Phone 596-4323

INTELLECTUAL/DEVELOPMENTAL DISABILITIES

"Developmental disabilities" means disabilities attributable to intellectual disability, cerebral palsy, epilepsy, autism, or any other neurologically disabling condition closely related to intellectual disability and requiring treatment similar to that required by intellectually disabled individuals if the disability originated before the person attained age 18, has continued or can be expected to continue indefinitely, and results in the person having a substantial disability. (53-20-202 MCA)



The state of Montana assists children and adults with developmental disabilities through the Medicaid program. The Department of Public Health and Human Services (DPHHS) operates Medicaid home and community based waivers designed to help these individuals to live, work and participate in their communities.

SERVICE PROVIDERS The state contracts with about 60 private, non-

profit agencies throughout the state to provide the services needed to support those with developmental disabilities in their communities. Services include a wide array of residential and employment opportunities for adults, family education, and support services for children and their families based on individual preferences, needs and abilities. All services are designed to help those with disabilities live with dignity and respect, participate in life decisions, participate in their communities, do meaningful work, and live as independently as possible. Services are provided in accordance with a personal support plan that identifies the support and services needed by each individual to function as independently as possible in the community. Services include residential group homes, a wide range of work activities, supported employment and vocational rehab, intensive day activities, transitional living, supported living, transportation, personal care, adult day care and other services.

STAFFING Service provider agencies employ large numbers of direct care workers as well as administrative and professional staff. Agencies receive most of their funding from Medicaid, which does not adequately cover the costs associated with providing the services and makes it difficult to provide sufficient wages and benefits to workers to attract and retain direct care and other staff. The problem is exacerbated in the eastern part of the state because of the pressure on wages and living costs associated with the Bakken.

FUNDING These services are funded mostly through the Medicaid program. The state general fund provides about one-third of the funding, while the federal government provides about two-thirds. There is also some funding available from federal social services block grants. Medicaid rates are not adequate to cover costs that continue to increase and over which provider agencies have little or no control - food, utilities, health insurance, liability insurance and the like. Funding also does not allow for wage and benefit increases that are needed to recruit and retain staff.

NUMBER OF PEOPLE SERVED About 2,700 individuals are receiving services under the waivers at any given time.

WAITING LIST Over 1,000 additional individuals are on a waiting list for needed services. Unlike other programs in Medicaid, individuals with developmental disabilities are provided services over their lifetime. This means that service slots do not open up often. Unless the legislature provides specific funding to serve those on the waiting list, there will be no progress toward reducing the number of people waiting for services.

KEY ISSUES

- Medicaid rates paid to the private agencies who contract with the state to provide services need to be increased to account for inflation and to allow for wage and benefit increases for their direct care workers who provide services and support to people with developmental disabilities.
- Funding should be provided to address the waiting list so those needing services can receive the help they need. Failure to assist when help is needed can lead to the need for more intense services later.

MONTANA ASSOCIATION
MT CDS
OF COMMUNITY
DISABILITY SERVICES

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MEDIA ADVISORY:

May 6th, 2014

For more information or to get a full schedule contact:
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“A DAY AT THE CAPITOL”

ORGANIZED BY PARENTS OF CHILDREN WITH DISABILITIES

On the heels of the successful Legislative Candidates' Forum on Disabilities, Great Falls families, have organized to further advocate for their disabled children. “A Day at the Capitol” is the first event of many in an effort to improve life for children with disabilities, by connecting with Montana decision makers at the state level. Parents of children with special needs have planned to gather, as a group, at the Capitol on Friday, May 9th. They will be meeting with public officials from the Executive and Legislative branches of government .

The goal of “A Day at the Capitol” is to improve the state system of services for disabled children. We will make connections with decision makers while building relationships and understanding. We believe our direct experience is valuable. As special-needs mother, Joyce Moore, puts it: “Raising a child with a disability is a very difficult, full-time job. Parents should be able to use their energy to care for their child, not fight for services in a system that is not functioning properly.” We hope to work shoulder to shoulder with our public officials, crafting and improving policies. We realize now is the time to get involved.

The day's events will begin with families meeting members of the CFHHS (Children, Families, Health, and Human Services) Legislative Committee, over lunch. The intent of the lunch-meeting is for families to share, with the committee, issues they face with their children, every day, with the hope of building understanding. Officials from The Department of Public Health and Human Services and Governor Bullock's office are planning to join the lunch and discussion. Other activities include a meeting with the Office of Public Instruction, a press conference and, finally, testifying at the CFHHS Committee meeting.

WHO: The Arc Montana families

WHAT: “A Day at the Capitol”

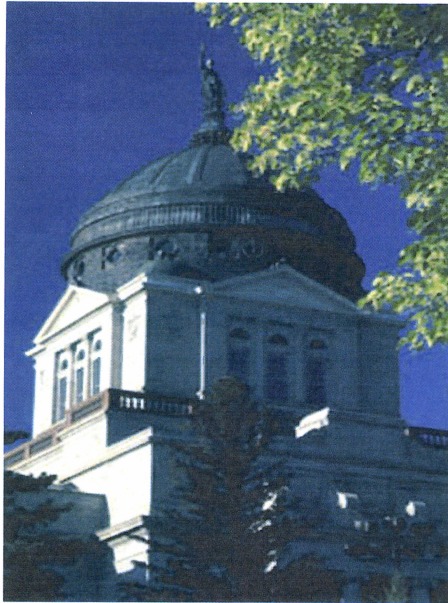
WHEN: May 9th Press conference at 1:30pm

WHERE: The Capitol Room 172 1301 6th Ave E. Helena



An AWARE Inc. commitment to people with intellectual and developmental disabilities.

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetime



"A DAY AT THE CAPITOL"

"A Day at the Capitol" is the first event of many in an effort to improve life for our children by connecting with legislators. Whether you would like to publicly tell your story, or play a supporting role, we invite you to attend. (Public speaking experience is not required). Please feel free to join us for all, or part, of the day.

"A Day at the Capitol" - Your experience is valuable.

THEY NEED TO HEAR FROM YOU!

PLEASE JOIN US!!!

WHERE:	The Capitol Room 172 1301 6th Ave E. Helena
WHO:	Montana families
WHAT:	"A Day at the Capitol"
WHEN:	May 9th 10:00AM

10:00am-11:30	Training -Time to practice, network, drink coffee. Training by Jeanne Brown, ambassador on Social Security and Grandmother raising granddaughter with disability. Rm 172
11:30	Set up lunch Rm 172
11:45-1:00	Lunch & conversation with the Children, Families, Health and Human Services Legislative Committee members, officials from Human Services and Governor Bullock's office. Rm 172
1:30-2:30 pm	Meet with the press Rm 172
3:00pm	Meeting w/ Terry Kendrick Office of Public Instruction-Special Projects. Office of Public Instruction 1300 11 th Ave Helena. Superintendent's conference room.
4:00-4:15	Children, Families, Health, and Human Services Committee meeting. Public testimony. State Capitol Rm 152



Mary Caferro, Director

The Arc Montana

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